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Award Number: DAMD17-01-1-0565

TITLE: Decision Making of Women with Recurrent Breast Cancer

PRINCIPAL INVESTIGATOR: Penny F. Pierce Ph.D.

CONTRACTING ORGANIZATION: University of Michigan
Ann Arbor, Michigan 48109

REPORT DATE: October 2005

TYPE OF REPORT: Final

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

REPORT DOCUMENTATION PAGE

Form Approved
OMB No. 0704-0188

1. REPORT DATE *(DD-MM-YYYY)*	2. REPORT TYPE	3. DATES COVERED *(From - To)*
01-10-2005	Final	10 Sep 2001 - 30 Sep 2005

4. TITLE AND SUBTITLE
Decision Making of Women with Recurrent Breast Cancer

5a. CONTRACT NUMBER

5b. GRANT NUMBER
DAMD17-01-1-0565

5c. PROGRAM ELEMENT NUMBER

6. AUTHOR(S)
Penny F. Pierce Ph.D.

E-Mail: pfpierce@umich.edu

5d. PROJECT NUMBER

5e. TASK NUMBER

5f. WORK UNIT NUMBER

7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)
University of Michigan
Ann Arbor, Michigan 48109

8. PERFORMING ORGANIZATION REPORT NUMBER

9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES)
U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

10. SPONSOR/MONITOR'S ACRONYM(S)

11. SPONSOR/MONITOR'S REPORT NUMBER(S)

12. DISTRIBUTION / AVAILABILITY STATEMENT
Approved for Public Release; Distribution Unlimited

13. SUPPLEMENTARY NOTES

14. ABSTRACT: Purpose: The intention of this study is to close the gaps in our knowledge regarding the decision-making experiences and challenges women face when breast cancer recurs. The specific aims of this qualitative study are to: (1) provide a robust description of decision making processes of women confronting recurrent disease, (2) describe preferences and values instrumental in the selection of treatment options (e.g., clinical trials, alternative therapies, adjuvant therapies, or no treatment), (3) describe the manner in which previous treatment decision making experiences are, or are not influential, and lastly, (4) describe the appraisals of decision processes and outcomes to identify those factors that contribute to, or impede, quality decision making. Scope: Fifty women recently diagnosed with recurrent disease were recruited to participate in a semi-structured interview to describe her decision making experiences. The Michigan Assessment of Decision Style (Pierce, 1995) was administered to provide a measure of pre-decision behavior. Major Findings: These data reveal an emerging description of the psychology of making repeated therapeutic decisions for recurrent disease. The phenomenon of *Looking Forward: Looking Back* captures this unique decision experience which is influenced by both an optimistic and hindsight bias that appears to preserve psychological well being.

15. SUBJECT TERMS
Recurrent Breast Cancer, Decision Making, Psychological Stress, Decision Outcomes

16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT	18. NUMBER OF PAGES	19a. NAME OF RESPONSIBLE PERSON
a. REPORT	b. ABSTRACT	c. THIS PAGE			19b. TELEPHONE NUMBER *(include area code)*
U	U	U	UU	22	USAMRMC

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INTRODUCTION: The purpose of this study is to close the gaps in our knowledge regarding the decision making experiences, challenges, and frustrations of women when breast cancer recurs. It is important to discover how women make decisions in this stressful and uncertain context to determine what they find troublesome and difficult, how they can best convey their values and preferences in the choices they make, and to identify ways in which their prior decision making experience with the initial diagnosis affects their current decision behavior. Therefore, the specific aims of this project are to: (1) provide a robust description of decision making processes of women faced with recurrent disease to generate hypotheses for future testing, and ultimately, for the design of prescriptive decision support interventions, (2) describe preferences and values instrumental in the selection of treatment options (e.g., clinical trials, alternative therapies, adjuvant therapies or no treatment), (3) describe the manner in which previous treatment decision making experiences are, or are not influential, and lastly, (4) describe the appraisals of decision processes and outcomes to identify those factors that contribute to, or impede, quality decision making. The theoretically challenging task is to find an explanation that accounts for the relative ease by which some women make a complicated and serious medical decision, and the overwhelming, difficult, and stressful experience of others (Pierce, 1996). From a clinical perspective, it is important to understand the processes which lead women to select unnecessarily aggressive therapies or decline therapy altogether from a sense of despair rather than reasoned deliberation. The ultimate objective of this preliminary descriptive work is to support the design of decision support interventions to enhance quality decision making in this vulnerable population.

BODY: This section of the report shall describe the research accomplishments associated with each task outlined in the approved Statement of Work. The original and revised Statement of Work appears in Appendix A.

- This study addressed four of the major gaps in the literature concerning the psychology of choice when facing recurrent breast cancer. We currently know very little about the following: (1) the unaided decision making in naturalistic real-world settings, (2) how the decision experience for early stage breast cancer influences decision making for recurrent disease, (3) the psychological experience of decision making when cancer recurs, and (4) how women reconcile expectations with reality to maintain psychological well being.

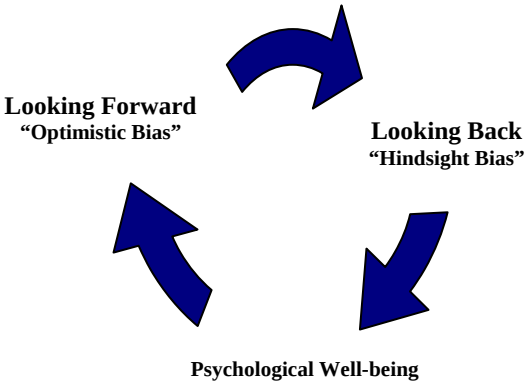
- Women's recognition of the acute threat to life that occurs with recurrent disease prompts decisions regarding many aspects of their lives at the time of diagnosis. This unique cohort of women reveals a potentially untapped reservoir of resources that are activated by the recognition they have an opportunity to make life-changing choices. These women appear to be coping in more effective ways; they are engaged in their treatment; and self-report an unexpected enthusiasm about taking control of their lives. Although a small group of women experienced very negative responses to the diagnosis, many other women expressed extraordinary resilience and optimism (e.g., Charles, Redko, Whelan, Gafni & Reyno, 1998). It is not clear why some women were able to mobilize their resources to confront cancer again and others were regrettably overwhelmed. Taken together, there is a need to focus greater attention on these two responses to identify the most salient contributing factors that enable or deter women from participating in these decisions and appraising them in positive ways. Within both groups, we need to gather additional information regarding the psychological mechanism of both optimism as well as pessimism in decision behavior to be able to tailor decision support interventions that will help them mobilize decisional coping in a way we have not heretofore recognized.

- Striking differences were identified between young women (38-55) and older women (56-80) in their responses to having to deal with cancer a second (third or fourth) time, and the unique ways in which age and life experiences influence their decision making processes as well as their satisfaction with their initial treatment. Older women (these ages are approximations) appear to have a unique resilience and positive approach to recurrent disease, in contrast to younger women who experience and express much greater distress disappointment and fear. Further exploration of the experiences of the elder group of women (over 65 years of age) could explore their positive coping strategies as a way of learning more about why they appear to be able to successfully deal with a recurrence.

- Contrary to the predictions in the literature (Janis & Mann, 1977; Landman, 1993; Loomes & Sugden, 1982; Zeelenberg, 1999) that a certain proportion of women would experience decisional regret at the time of recurrence, these data reveals something quite different. In contrast, these subjects reveal an interesting psychological construct that merits further development with respect to coping with recurrent and metastatic disease. That is, a majority of women, despite experiencing a recurrence do not believe they would change their initial decisions for the treatment of early stage breast cancer. This psychological process allows women to acknowledge that their initial decision was the best possible option at the time. Yet despite having cancer again, they are aware that any self-recrimination or doubt at this point about what they might have done differently would not be in their best interest. These data promise to increase our understanding of psychological resilience in the face of setbacks as well as the ways in which postdecision appraisal influences psychological well being. A manuscript in preparation is addressing this finding.

- The theme describing the concept of *Looking Ahead vs. Looking Back* is salient in this sample because they are uneasily positioned between the past with the memories and emotions of dealing with cancer while facing the decision again only this time with additional uncertainty and complexity (see Figure 1). Conceptually, this is an ideal sample within which to elaborate our understanding of these unique decision processes and the ways in which they influence psychological well being. A manuscript describing this theoretical formulation is in preparation.

Figure 1. A Preliminary Theoretical Model



- *Looking Forward and Looking Back* are conceptually different psychological processes and are subject to different biases when making a decision or appraising the outcome of the decision once it becomes reality.

- The *Looking Forward* phenomenon of women with recurrent disease is distinct from that of women with early stage breast cancer and it surprisingly optimistic despite the realities incumbent with a recurrence. It involves one's expectations and desire for a good outcome despite the current circumstances. The psychological concept of "optimistic bias" serves to preserve psychological well being and protects one from overwhelming threat (e.g., Klein & Helweg-Larsen, 2002; Kos & Clarke, 2001). In *Looking Forward* women expressed confidence regarding their current treatment decisions and expressed a surprising level of optimism about the future. This has a protective psychological effect and appeared to have a ripple effect on a multitude of life choices (e.g., work, family life, etc.) Exploration of this phenomenon is worthy of further study as it highlights the role of optimism in the face of a profound setback and disappointment and enhances our understanding of decision appraisals and their influence on the coping of women with recurrent disease as well as other life-threatening cancers (e.g., Steginga & Occhipinti, 2006).

- The *Looking Back* phenomenon was captured from narratives regarding how women look back on their decision making processes for early stage cancer. About half the sample thought about, or was told, about the possibility of recurrent disease when making their initial therapy decisions. A majority of women were optimistic about the success of their initial treatment and did not expect to experience a recurrence. About half the sample was "surprised" to be facing cancer again and when cancer did recur, younger women experienced more distress than older women (Ofir & Mazursky, 1997). The psychological processes of post-decision appraisals (looking back on the initial diagnosis) seek to preserve self-esteem and emotional well-being. Very few admitted a "mistake" in the selection of an initial treatment although many would now either choose differently or go about the process differently (e.g., collect more information). Interestingly, women did not express regret or remorse at their earlier decision but rather reported that they did the best they could with the information that was available at the time. The psychological phenomenon of "hindsight bias" is one of overconfidence and despite the outcome, women tended to reframe the outcome in a way that preserved their emotional well being (e.g., Christensen-Szalanski, 1991; Fischhoff, 2003). The "hindsight bias" was particularly salient in this sample. Psychologically, this bias represents a revision of memory to fit new information; it is a reconstruction bias in which self-serving tendencies can influence the reconstruction selectively for favorable and unfavorable outcomes. A person's tendency, after learning about the actual outcome of a situation is to distort a previous judgment in the direction of this new information and this is particularly robust in this group.

- These data reveal an emerging psychological description of recurrent disease which includes the following concepts: (1) the experience of recurrent disease diminishes the belief in a cancer free life and revises expectations of the future, (2) it brings personal values into sharp focus and serves to define new life goals and stimulate numerous other decisions about work, family, lifestyle that focus on quality of life, and (3) it encourages positive reflections regarding her participation and self-determination in making important treatment decisions. In future studies,

these concepts could be measured to provide a metric of well-being over the course of extended illness and/or following interventions designed to support women's decision making in ways that enhance psychological well being with recurrent disease.

- Results of the study identified a vulnerable cohort of younger women who appeared to experience more distress and decisional conflict regarding treatment, as well as disappointment and fear regarding recurrent cancer. Younger women appear to need more instrumental decision support to achieve confidence in the decisions they are now facing.

Negative and Positive Findings

- No difficulty with recruitment of subjects once the clinical site was opened and clinicians became familiar with the project; women were eager to discuss the topic and many reported a benefit from their participation. Clinicians were extremely helpful in recommending suitable women and supported the project because they recognized this is a particularly vulnerable group of women who require decision support.

- Overall, this study had numerous positive findings that are discussed in this document. In addition, issues of recruiting and interviewing (using the think aloud technique) women in this stressful situation have provided valuable methodological information about conducting research with vulnerable samples.

Problems Accomplishing Tasks

- Prolonged IRB approval process (3 review committees required)

- The study was delayed due to the absence of the PI's military service at the beginning of Operation Iraqi Freedom and Operation Enduring Freedom.

Recommended Changes or Future Work to Better Address the Research Topic

- This qualitative study is a necessary first step toward understanding the decision making processes of women facing recurrent breast cancer. With the identification of relevant concepts and a tentative theoretical framework, future studies can select appropriate measures of these concepts (e.g., hindsight and optimistic bias, resilience, coping) and explore their linkages with decisional appraisal, behavior and outcomes. Ultimately, future work will design tailored decision interventions (preferable with the vulnerable younger women) that will accomplish the following: (1) support decisions that are based on the best available and personally-relevant information (e.g., values and preferences), (2) help women avoid predictable decision hazards of uncertain, stressful, and emotional-laden health care choices, (3) target vulnerable women in greatest need of decision support, (4) address pre- and post-decision biases that may negatively impact decision quality, and (5) bolster the naturalistic decision behavior that serves to preserve their psychological integrity.

KEY RESEARCH ACCOMPLISHMENTS:

- Negotiated a clinical site for recruitment of potential subjects.

- Development of an interview schedule that was successful in obtaining quality narratives of women's decision making processes. The interview schedule and the Michigan Assessment of Decision Style (Pierce, 1995) are being included in a pilot project focusing on the decision making

experience of older women (over 65) in Israel (interview and instrument has been translated into Hebrew).

- Interviewed 50 women between the age of 31 and 82 in their homes or the clinic, whichever she preferred.
    - Traveled distances up to 200 miles roundtrip to accomplish the interview
    - Transcribed and analyzed transcripts of interviews using the constant comparative method
- Tested the "think aloud" technique in a naturalistic setting to capture the cognitive processes of actual decision behavior (Biggs, Rosman & Sergenian, 1993; Huber, Wider, & Huber, 1997; Williamson & Ranyard, 2000).
- Identified themes from the qualitative data (discussed previously)
- Identified areas where women require tailored decision support.
    - Identified vulnerable women who would benefit from tailored decision support (e.g. younger women and those with high decisional conflict or uncertainty).
- Identified ways in which bias and optimistic bias serve as psychological coping mechanisms to deal with decisional regret and disappointment regarding treatment decisions for breast cancer (e.g., Bell, 1982; Zeelenberg, 1999).

REPORTABLE OUTCOMES:

- Peer-reviewed Oral Presentations
    a. *Looking Ahead – Looking Back: Decision Making of Women with Early Stage and Recurrent Breast Cancer.* International Symposium on Breast Cancer, April 2005, Tianjin, China.
    b. *Decision Making of Women With Recurrent Breast Cancer*. 23rd International Congress of Nursing, May 2005, Taipei, Taiwan.
- Invited Presentations
    a. *Decision Making of Women With Recurrent Breast Cancer.* Washtenaw Chapter of the Oncology Nursing Society, November, 2005.
- Peer-reviewed Poster Presentations

1. *Decision Making of Women with Recurrent Breast Cancer.* Era of Hope Meeting, Department of Defense Breast Cancer Research Program Meeting, June, 2005, Philadelphia, PA.
2. *Naturalistic Decision Processes among Women Facing Recurrent Breast Cancer.* 27th Annual Meeting of the Society for Medical Decision Making, October 2005, San Francisco, CA.

- Proposed Work

1. Manuscripts in preparation
    - *Looking Ahead – Looking Back: The Psychology of Decision Making When Cancer Recurs*

- *Providing Decision Support for Women With Recurrent Breast Cancer*

2. Proposal Preparation

- Findings of this study will be used to support the submission of a project to study women with recurrent and metastatic breast cancer to explore linkages between decision making behavior and quality of life.

CONCLUSIONS: This project focused on the decision experiences of women who find they are confronting breast cancer once again when a recurrence is detected and additional treatment decisions must be considered. We do not currently appreciate how the disappointment, fear, and perhaps even regret influence women's decisions regarding treatment in this highly threatening and emotional context. Robust descriptions of naturalistic decision processes (Pierce & Hicks, 2001) lead to the construction of testable theoretical models representing decision processes of this vulnerable group of women. A descriptive empirical model derived form these qualitative data will provide a structure that allows health professionals to evaluate the ways women make decisions in such contexts, and, (a) induces us to recognize the rules or strategies that patients use, allowing us to help patients avoid potential source of error or bias; (b) helps us make better assessments about when to intervene in the decision-making process and when not to intervene; and (c) allows us to access the relationship between the way a woman made an initial treatment decision and how she currently appraises those choices with all the advantages of hindsight. A unique approach to the study of complex real-world decisions is called for to better understand the constraints on human logic and rationality in life-threatening health care circumstances. From a clinical perspective, the results of this study will inform patients and clinicians alike regarding the continuum of decision-making processes from initial treatment in early stage to recurrent disease where the complexity is increased and the emotional resources are compromised more than ever before. Future studies can build on these findings to prescribe relevant, appropriate, and timely decision support to reduce the psychological, physical, and cognitive burden on patients and their families. Such deliberative and tailored decision support is intended to help women select appropriate preference-based treatment, enhance the likelihood of positive post-decision outcomes and impact quality of life in a meaningful way.

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APPENDICES

APPENDIX A: Statement of Work (original and revised)

APPENDIX B: Study Questionnaire

APPENDIX C: Interview Schedule

APPENDIX A

SCHEDULE OF WORK (ORIGINAL AND REVISED)

	2002				2003								
	SEP	OCT	NOV	DEC	JAN	FEB	MAR	APR	MAY	JUNE	JULY	AUG	SEP
TASK													
Build Research Team													
• ***Recruit Research Interviewers***													
• ***Provide Interviewer Training***													
Develop Recruitment Protocol													
• *Create Recruiting Brochure*													
Develop Interview Protocol													
Develop Protocol													
• *Train Interviewers on Protocol*													
• *Revise Protocol as Needed*													
Obtain IRB Approvals													
• *University of Michigan Hospital*													
• *St. Joseph's Mercy, Pontiac*													
• *DoD*													
Develop Recruitment Sites													
• *University of Michigan, AA*													
• *Protocol Review Committee U M*													
• *St. Joseph's Mercy, Pontiac*													
Data Collection													
• **Interviews from Ann Arbor**													
• **Interviews from St. Joseph's**													
• *Transcribe Interviews*													
Qualitative Data Analysis													
• *Train on Coding & Analysis*													
• *Develop Coding Scheme*													
• *Data Analysis of Transcripts*													
Publications													
• *Theoretical Paper*													
• *Data-based Paper*													
• *Clinically-relevant Paper*													
Submit Final Report													

	2004				2005						
	SEP	**OCT**	**NOV**	**DEC**	**JAN**	**FEB**	**MAR**	**APR**	**MAY**	**JUNE**	**JULY**
TASK											
Data Collection											
• **Interviews from Ann Arbor site**											
• *Transcribe Interviews for Analysis*											
Qualitative Data Analysis											
• *Train on Coding & Analysis*											
• *Develop Coding Scheme*											
• *Data Analysis of Transcripts*											
Publications											
• *Theoretical Paper- Decision Making*											
• *Data-based Paper- Decision Making*											
• *Clinically-relevant Paper*											
Submit Final Report											

APPENDIX B

SURVEY QUESTIONNAIRE

Defining Decision Support for Women With Recurrent Breast Cancer

Penny F. Pierce PhD, RN
Principal Investigator
The University of Michigan School of Nursing
400 North Ingalls
Ann Arbor, MI 48109
(734) 615-2997
pfpierce@umich.edu

This project is funded by a grant from the U.S. Army Breast Cancer Research Program (BC996510; DAMD17-01-1-0565)

DEMOGRAPHIC AND BACKGROUND INFORMATION

1. Please write down ***today's*** date.....___ ___/___ ___/___ ___
MONTH DAY YEAR

2. What is your date of birth? .....___ ___/___ ___/___ ___
MONTH DAY YEAR

3.What is the highest grade of school or year of college you have completed?

Circle the appropriate number

Grades of School	College/Yrs. of School
01 02 03 04 05 06 07 08 09 10 11 12	13 14 15 16 17+

4.Taking into consideration all sources of income including wages, pensions, unemployment compensation, and other sources, what was the total income of your family household before taxes last year?

Circle the appropriate number

01. $4,999 OR LESS
02. $5,000 - 9,999
03. $10,000 - 14,999
04. $15,000 - 19,999
05. $20,000 - 24,999
06. $25,000 - 29,999
07. $30,000 - 34,999
08. $35,000 - 39,999
09. $40,000 - 44,999
10. $45,000 - 49,999
11. $50,000 - 54,999
12. $55,000 - 59,999
13. $60,000 - 64,999
14. $65,000 - 69,999
15. $70,000 - 74,999
16. $75,000 - 79,999
17. $80,000 - 84,999
18. $85,000 - 89,999
19. $90,000 - 94,999
20. $95,000 - 99,999
19. $100,000 - 124,999
20. $125,000 - 149,999
21. $150,000 OR MORE

5. Which of the following possibilities best describes your **present** marital status?

Circle only one answer

1. Never Married
2. Living with a partner
3. Married
4. Geographically separated due to conflicting military assignments
5. Separated (Breakdown of marriage)
6. Divorced (Due to conflicting military commitments)
7. Divorced (Breakdown of marriage)
8. Widowed

6. Are you currently living with your husband or with a partner?

1. Yes 5. No

The following are questions about your ethnic or racial background:

7. How would you describe your ethnic or racial background?

Please circle all that apply

1. White
2. Black/African American
3. American Indian, Eskimo or Aleut
4. Asian or Pacific Islander
5. Other, specify _____

8. Are you of Hispanic descent?

1. Yes 5. No

9. What is your current employment?

1. Full time
2. Part time
3. Unemployed
4. Student

The following are questions about your history of breast cancer

10. When were you first diagnosed with breast cancer?

---

11. What was the type of breast cancer that was diagnosed at that time?

---

12. What treatment did you select at that time?

MICHIGAN ASSESSMENT OF DECISION STYLE
(Pierce, 1995)

Following are a few statements that describe typical decision making behavior of people considering medical treatments. Thinking of the decision you are about to make, circle the number on the scale that most closely resembles the way you are thinking about the decision.

	1 No, definitely not	2	3 Neither yes or no	4	5 Yes, definitely
1. I would make a quick decision once I was told what my options were.	1	2	3	4	5
2. I would follow the recommendations of my physician	1	2	3	4	5
3. I would agree to the option that seemed the most reasonable to me at the time.	1	2	3	4	5
4. I would develop a plan for gathering further information	1	2	3	4	5
5. I would read magazines and articles about different treatments.	1	2	3	4	5
6. I would read scientific articles about the treatments that were being offered to me.	1	2	3	4	5
7. I would spend as much time as I could gathering information.	1	2	3	4	5
8. I would prefer to seek advice from specialists.	1	2	3	4	5
9. I would ask about the risks involved with each treatment alternative.	1	2	3	4	5
10. I would carefully consider the risks of each option as I was making a choice.	1	2	3	4	5
11. I would want to know the possible outcomes of each alternative that was being offered to me.	1	2	3	4	5
12. I would ask a lot of questions concerning the treatment options.	1	2	3	4	5
13. I would want someone else to make the decision for me.	1	2	3	4	5
14. I prefer, in situations like this, that someone else tells me what to do.	1	2	3	4	5
15. I prefer not knowing the possibility that unexpected things could happen to me.	1	2	3	4	5
16. I believe that what will happen, will happen and there is little I can do to change things.	1	2	3	4	5

APPENDIX D

INTERVIEW SCHEDULE

Defining Decision Support for Women with Recurrent Breast Cancer

INTERVIEW SCHEDULE

Introduction

Hello Ms./Mrs./Dr _____.
My name is _____and I am from the University of Michigan School of Nursing. We are conducting a research project that is intended to help us better understand how women like yourself make decisions for breast cancer when they are faced with the diagnosis a second time. In this study, we are trying to learn more about how women's experiences of making these choices, in what ways it might be different or similar to the first diagnosis, and how their values and preferences get communicated to those who care for them. If you would be interested in participating in the study, I would be happy to review the informed consent procedure with you at this time.

If no ➔ Thank the patient for her time

If yes ➔ Review the Informed Consent document, obtain a signature, and provide a copy to the subject

Set a date and time for the interview if the current setting is not appropriate

I would like to ask you to tell me about how you made the decision regarding treatment the first time you were diagnosed with breast cancer and how you are going about making a decision regarding treatment at this time. We can take a break when you wish or end the interview whenever you want to. Just let me know, at any time, if you would like to stop. If I ask a question you prefer not to answer, that's fine. You can just say "pass," and we'll move on.

Do you have any questions for me at this time?

OK then, we can begin if you are ready.

Can you tell me about the first time you were diagnosed; when that was and how you remember making the decision.

[Interviewer: allow the subject to complete her story in her own words at her own pace. Use the following probes only if she has not addressed the issue]

Probe ➔ Do you remember the kinds of things that were important to you at the time you were making that decision?

Probe ➔ Did you find that making the decision was difficult? If so, what made it difficult for you?

Probe ➔ Who or what helped you make the decision?

As time has passed, what do you think now about the decision you made?

Probe ➔ What are you most pleased/satisfied with about that decision?

Probe ➔ Is there anything about how you went about making that decision that, on reflection, you would like to change now?

Probe ➔ What "words of wisdom" would you pass along to other women who may find themselves in the same situation?

Probe ➔ Was there anything that health professionals did to help you make your decision at that time?

Let's move forward to where we are today…

What is your reaction to facing this decision once more?

Probe ➔ In what ways was this decision different from the first time?

Probe ➔ Did you find that your experience from the first time helped or hindered you in making this decision? In what ways?

Probe ➔ What did you learn about making decisions at that time that is helpful to you now?

Probe ➔ What suggestions do you have for health professionals that might be helpful to them as they counsel and support patients in making treatment decisions such as the one you are facing?

Is there any part of your experience that we did not talk about that you would like to share at this time?

Do you have any last questions for me?

Thank you for taking the time to share your experience with me.

[Give the subject the envelope containing the gift certificate of her choice]